

Lifelong Care for Children with Chronic Conditions: A discussion series

Re-imagining the Package of Care for Children Subgroup May 14, 2021

Child Health Task Force Today



from





1500+ members

300+ organizations



Working together in **10** subgroups



Focused on 5 themes of work

Series objectives

- Share and get feedback on UNICEF's working "Integrated Chronic Lifelong Care for Children and Adolescents" framework
- Present case studies on specific chronic conditions
- Draw lessons for broader programming and implementation

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May 2021

Integrating Chronic Lifelong Care for Children and Adolescents in Primary Health

Ganade Putta



Presentation Outline







Rationale

Framing in the broader context of Child Health Epidemiology and PHC Conceptual Graphic of the Chronic Care Model (CCM) for Children and Adolescents Ongoing processes towards guidance development

Rationale

- Chronic Conditions affecting Children and Adolescents: HIV, Diabetes, Rheumatic Heart Disease, Asthma, Disabilities, Sickle Cell Disease, Cancers, Hep B, Syphillis
- In contrast with high-income countries, Chronic Care for children and adolescents is a less-developed area in low-and-middle-income countries
- These countries have typically focused on "episodic" management of common childhood illnesses that significantly contribute to child mortality
- With shifting epidemiologies, in part due to improving economies and gains in child mortality; and with UNICEFs focus on a thrive and transform agenda over and above survival; chronic conditions come more into focus.

DALY's by NCDs, Injuries, and communicable/nutritional disorders in the 1st two decades of life

Burden of diseases/disorders and NCDIs varies by economic income



Figure 1: Importance of NCDI disease burden for the poorest billion versus higher-income populations, adapted from the Bukhman, 2020 (Lancet NCDI Commission Report) NCD=non-communicable disease. DALY=disability-adjusted life-year. YLD=years of life with disability. YLL=years of life lost. HIC=high-income countries. UMIC=upper-middle-income countries. UMIC=low-income countries. PB=poorest billion. NCDI=non-communicable disease and injury.

Embedding Chronic Lifelong Care Models for Children & Adolescents in PHC

Well Child and Adolescent

Acutely sick or afflicted Child and Adolescent

Chronically sick or afflicted Child and Adolescent



LIFECOURSE	Pregnancy	Birth	Infancy (0-1 yrs)	Early Childhood (1-4yrs)	Middle Childhood (5-9)	Adolescence (10-19)
Routine entry points	ANC	Immunization	Immunization, well and sick baby clinics, nutrition services School & health s			health services
Community level	Community, Civil Society & Multi-Sectoral engagement Health literacy (awareness raising, prevention messaging) for chronic diseases Early detection of risk and referral Peer and treatment support					
Primary health facility level	Screening in (HIV, SCD) Newborn screen metabolic	n pregnancy , CHD, CS) ning for genetic conditiONS	Early screening, detection and diagnosis Early interventionsTransition of car Adherence risk management(Asthma, CHD, Childhood cancer, Congenital Syphilis, Developmental Delays & Disabilities, HIV, RHD, T1 & T2 diabetes)Transition of car Adherence risk management			Transition of care Adherence risk management Adolescent friendly services
	Developmental monitoring, treatment monitoring & longitudinal tracking					
Specialized Care	Specialized care e.g. surgery, chemo/radiotherapy Management of complicated cases, treatment failures					



Overview of process underway



CONGENITAL HEART DISEASE -A CASE FOR POPULATION HEALTH APPROACH

Bistra Zheleva Children's HeartLink

May 2021

Children's HeartLink

Vision: Children around the world have access to high-quality heart care

Mission: We save children's lives by transforming pediatric heart care in underserved parts of the world



Advocacy





Patient Care Pathways











2030 Targets: (1) End preventable childhood deaths



• NM, 12 per 1,000 live births

U5M 25 per 1,000 live births
 Reduce by 1/3 premature mortality from NCDs
 A chick of UHC including financial rick protection

Achieve UHC, including financial risk protection
 Substantially increase health workforce in LMICs



Child mortality by income level of country, 1990 to 2017



The child mortality rate measures the share of children that die before reaching the age of 5.



Source: World Bank

OurWorldInData.org/child-mortality/ • CC BY

ildren's HeartLink®

Decreasing U5MR Will Reveal the Constant Burden of Heart Disease



A Case for the Invisible Child http://theinvisiblechild.childrensheartlink.org/



Causes of death in children >1 year, 2019 (by death rate per 100 000)

	Both sexes, 28-364 days, 2019, Deaths per 100,000						
	his ry	MB LI	MB IM,	MIS UNI,	tarth.		
Lower respiratory infect	7	1	1	1	1		
Diarrheal diseases	20	2	2 2 4		2		
Malaria	116	3	3	48	3		
Congenital heart	2	7	4	2	4		
Meningitis	19	6	5	16	5		
Whooping cough	33	5	6	17	6		
Protein-energy malnutrition	46	4	7	11	7		
Other congenital	5	9	8	6	8		
Neonatal preterm birth	3	19	10	3	9		
SIDS 1		13	9	12	10		
Drug-susceptible TB 70		10	11	26	11		
Other neonatal 9		14	12	7	12		
Neural tube defects	10	11	13	13	13		
Measles 78		8	21	33	14		
Syphilis 45		12	14	20	15		
Digestive cong anomalies 11		15	15	9	16		
Neonatal sepsis	13	16	17	8	17		
Pulmonary aspiration	4	30	23	5	18		
Neonatal encephalopathy	14	22	16	10	19		
HIV/AIDS other	39	18	19	19	20		
lleus & obstruction	15	20	18	14	21		
iNTS	79	17	20	73	22		
Encephalitis	32	50	22	22	23		
Etromosomal unbalanced	6	24	29	21	24		
Down syndrome	16	25	28	15	25		







THE GLOBAL BURDEN OF CONGENITAL HEART DISEASE

GBDcompare tool, 2019 data



217,000 deaths from CHD globally



18.6 million DALYs

96% deaths in LMICs

70% (150,000) deaths were in **infants**



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Both sexes, 28-364 days, 2019, Deaths

	India	Rangladesh	Sri Lanka	Indonesia	China	
Lower respiratory infect	1	1	2	2	2	
Diarrheal diseases	2	3	12	1	9	
Congenital heart	3	2	1	3	1	
Whooping cough	4	4	10	4	28	
Protein-energy malnutrition	5	5	31	12	22	
Meningitis	6	15	13	6	11	
Malaria	7	113		59		
Other congenital	8	6	3	0	0	
SIDS	9	8	8			
Encephalitis	10	54	14		ath = 2010	
Drug-susceptible TB	11	10	33	iaia Chu ae	eaths, 2019	
Acute hepatitis A	12	32	103			
Other neonatal	13	20	11	otal: 38	152	
Falls	14	48	20	otan oo ,		
Neonatal preterm birth	15	23	4	1 voar: 26	600	
Acute hepatitis B	16	53	93			
Syphilis	17	7	32	a a mataly 16	710	
Neonatal sepsis	18	13	5	eonalai: 10,	///0	
lleus & obstruction	19	9	21	•		
Measles	20	21	15			
Drowning	21	18	29	18	29	
Venomous animal	22	56	66	93	86	
Digestive cong anomalies	23	14	7	13	6	
HIV/AIDS other	24	72	57	34	44	
Idiopathic epilepsy	25	37	30	62	35	



NCD mortality beyond SDG target 3.4

THE LANCET

HEALTH POLICY VOLUME 392, ISSUE 10152, P1072-1088, SEPTEMBER 22, 2018

NCD Countdown 2030: worldwide trends in non-communicable disease mortality and progress towards Sustainable Development Goal target 3.4





NCD Countdown 2030

Imperial College London

Children's

WHO 25×25 target & SDG 3.4 \rightarrow deaths from NCDs 30-70 age

2016

- ▲ 12.5 million deaths (30-70)
- ▲ 1.7 million deaths in <30 years of age Largest NCD-related cause: congenital heart anomalies (~ 230,000)

Ahead of by several factors: sickle cell disorders, ischemic heart disease, stroke, kidney diseases, and leukemia





RHD and CHD: Global YLDs and YLLs by Age, 2017



Zimmerman et al. Lancet CAH, 2020

The Cape Town Declaration on Access to Cardiac Surgery in the Developing World

Peter Zilla, MD, PhD, R. Morton Bolman, MD, Magdi H. Yacoub, MD, Friedhelm Beyersdorf, MD, Karen Sliwa, MD, PhD, Liesl Zühlke, MBChB, PhD, Robert S. D. Higgins, MD, Bongani Mayosi, MD, Alain Carpentier, MD, and David Williams, PhD

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in Africa, Faculty of Health Sciences, University of Cape Pediatrics and Child Health, University of Cape Town, C Maryland; Faculty of Health Sciences, University of Cape and Wake Forest Institute of Regenerative Medicine, W

The Mission: To urge all relevant entities withi commit to develop and implement an effective oping world through increased access to life-sa

Global Unmet Needs in Cardiac Surgery

Check for updates

Peter Zilla*, Magdi Yacoub[†], Liesl Zühlke[‡], Friedhelm Beyersdorf[§], Karen Sliwa^{||}, Gennadiy Khubulava[¶], Abdelmalek Bouzid[#], Ana Olga Mocumbi**, Devagourou Velayoudam^{††}, Devi Shetty^{‡‡}, Chima Ofoegbu*, Agneta Geldenhuys^{§§}, Johan Brink*, Jacques Scherman*, Henning du Toit^{||||}, Saeid Hosseini^{¶¶}, Hao Zhang^{##}, Xin-Jin Luo^{##}, Wei Wang^{##}, Juan Mejia***, Theodoros Kofidis^{†††}, Robert S. D. Higgins^{‡‡‡}, Jose Pomar^{§§§}, R. Morton Bolman^{|||||}, Bongani M. Mayosi^{¶¶¶}, Rajhmun Madansein^{###}, Joseph Bavaria****, Alberto A. Yanes-Quintana^{††††}, A. Sampath Kumar^{††}, Oladapo Adeoye^{‡‡‡‡}, Risenga Frank Chauke^{§§§§}, David F. Williams^{|||||||}

FIGURE 2. World map highlighting the contributing countries. In the circles, the number of cardiac surgeons per million population are depicted for each country.

Pediatric Cardiac Care in an Ideal Health System

			Level of Care				
Capacity	Continuum of Care	Village Health Center	First-Level Hospital	Second-Level Hospital	Third-Level Hospital		
Prenatal care and attended birth	Early Detection	×	x				
Universal screening and referral	Early Detection	x	x	x	x		
National congenital birth anomaly reporting mechanism	Surveillance	×	×	×	×		
Antibiotic availability and delivery	Prevention (RHD)	X	x	x	х		
Pulse oximeter	Diagnosis	×	х	х	x		
Echocardiogram, electrocardiogram, and chest x-ray	Diagnosis		×	х	×		
Fetal echocardiogram	Diagnosis			х	x		
Cardiac catheterization	Diagnosis & Treatment				x		
Cardiac medications availability and delivery	Treatment	×	x	x	x		
Spinal and general anesthesia	Treatment		x	×	x		
Open heart surgery	Treatment				x		
Intensive care unit	Treatment				x		
Infection control	Quality Assurance	×	x	×	x		
Continuing medical	Quality	×	x	X	x		

Children's HeartLink

Finding

The Invisible Child Childhood Heart Disease and the Global Health Agenda

Pediatric Cardiac Care Continuum

with associated decision factors (and decision makers)

Recognition	Diagnosis and prioritization	Referral	Stabilization and transport	Treatment	Follow-up
 Pediatrician Delivery center staff nurse RBSK nurse OBGYN Communities/ Family 	Pediatric cardiologistCardiologist	 Pediatric cardiologist RBSK nurse 	 Referring facility Transport team 	• Tertiary referral center pediatric cardiac team	 Pediatric cardiologist Pediatrician Community health worker/ nurse
Prenatal Screening (OBGYN) Newborn pre-discharge	Emergent cases (<i>critical CHD</i>) Urgent cases (<i>noncritical</i>	Acuity Geography	Safe transport of emergent and urgent cases	Surgery Treatment / Recovery	Short-term Follow-Up
Outpatient infant care symptom recognition	significant CHD) Elective cases (insignificant CHD)	Bed availability Tiers of expertise	Tracking and timely assessment of elective cases	Cath Lab Treatment / Recovery	Lifelong Follow-Up

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Zheleva, Int. J. Neonatal Screen. 6, 49; 2020

2016

POPULATION HEALTH APPROACH TO CHD

Improving timely screening, diagnosis and referral, increase access to tertiary care

Kerala

SDG3: Reduce child mortality 2/3 by 2020 and 50% by 2030

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HRIDYAM • For Little Hearts ...

Dr SREEHARI M State Nodal Officer (CH), NHM Kerala

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Yea

IMR Trend

- India has registered a significant decline in Infant Mortality Rate (IMR) in the last two decades.
- As per SRS 2019 , IMR of India has declined to 32 per 1000 live births.

Kerala Scenario

- Kerala's IMR was stagnant around 12 over a decade.
- As per SRS 2019, IMR Kerala is now down to 7 per 1,000 live births.
 - This reduction in IMR in Kerala is a result of efforts in bringing down anaemia among pregnant women, crucial interventions in the treatment of infectious disease among Newborn & infants, improved breast-feeding practises, better sanitation & hygiene, etc.

Why CHD has been given importance under IMR reduction strategy

IMR in Kerala while examined in detail revealed that Prematurity & Birth Asphyxia followed by Congenital Anomalies are the leading cause.

Among the congenital anomalies *Congenital Heart Disease* is the major contributor.

CAUSES OF INFANT MORTALITY IN KERALA 2013

• IAP study 2013

	33 MILLION	POPULATION, 14 ADMIN. UNITS (DISTRICTS)
Ŧ	0.5 MILLION EST.	CHILDREN BORN/YEAR
	12	INFANT MORTALITY RATE, PER 1,000 LIVE BIRTHS
26	6,000 EST.	INFANT DEATHS/YEAR
	8 PER 1,000 EST.	CHD INCIDENCE
	4,000 EST.	NEW CHD/YEAR
	1,000-1,200 EST.	NEW CRITICAL CHD/YEAR (25-30% OF ALL NEW CHD)
	650-750 EST.	INFANT DEATHS FROM CHD/YEAR
ч	500 EST.	ANNUAL KERALA-BORN INFANT CHD SURGERIES PERFORMED
}	42-50 % EST.	ESTIMATED INFANT SURGICAL TREATMENT COVERAGE
	7	EXISTING PEDIATRIC CHD SURGERY CENTERS, <i>2</i> PUBLIC AND 5 PRIVATE
	12	PEDIATRIC CARDIOLOGISTS
	10	PEDIATRIC CARDIAC SURGEONS

MILE STONES..

FUNCTIONAL BIRTH DEFECT SCREENING

Pulse Oximetry screening for Congenital Heart Disease at all 98 Public Delivery points

Pulse Oximetry Screening for CHD	PO Results to Hridyam portal	Combined with Physical Examination	Pulse Oximetry linked to HRIDYAM
PO Screening at 24 -48 Hours after birth & the set algorithm in machine detects PO passed/failed	Machine while connected to local computer with Internet Connectivity PO results against each child get updated in Hridyam & VBD portal	All failed cases by send to Pediatrician for specifically looking for any HEART MURMUR & LOW VOI FEMORAL PULSE	Failed cases will be alerted to DEIC who will arrange for confirmatory ECHO . The case will get registered in Hridyam and case followed up.
	USE Oximetry Data Dr Aute Galens Screent Based Scribt Based Control Con		<image/> <section-header><section-header><section-header><text></text></section-header></section-header></section-header>

State Hridyam

Home / VBD-Pulse Oximetry

SURGERY DONE 2018 & 19

Focus is on Infant Cases/ Neonates with complex diseases as a life saving program.

Sl. No.	INSTITUTIONS	2020	2019	2018	2017
1	SCTIMST	148	330	439	171
2	MCH KOTTAYAM	23	86	108	1
3	MCH KOZHIKKODE	4	13		
4	AIMS Cochin	357	298	225	16
5	Aster Medicity, Ernakulam	3	3	0	0
6	Lissie Hospital	234	85	49	13
7	Aster MIMS, Kozhikode	199	127	22	0
8	Believers Church Medical College	42	49	42	7
	SAT THIRUVANANTHAPURAM				
9	(Only interventions)	11	40	45	0
	Total	1021	1031	930	208

Cases Registered & Operated in 2017, 2018 & 2019

Follow up of Hridyam Cases in Community

Response initiated by treating team in case of emergencies through Hridyam portal

CHARACTARISTIC

• Uniqueness

• Focus

• The Main Success Factors are :

• Uniqueness, Importance & Focus

• Importance

- *First of this kind* comprehensive approach to Children with Congenital Heart Disease (CHD).
- **Cashless Treatment** in Private empanelled Hospitals.
- Web based Single registry
- For children with CHD Case, pre surgical and post surgical follow up

- Thrust given to early Diagnosis various means Ante natal Fetal Heart Screening, Pulse Oximetry combined with physical examination.
- Capacity building Technical and Infrastructure is also taken up as a

comprehensive program

- All surgical slots in Kerala made into a single pool & available for children registered under Hridyam
- Waiting period became finite

Those registered knows there tentative surgery dates

https://www.facebook.com/ hridyamkerala/

https://twitter.com/@Hridyam_kerala

www.hridyam.kerala.gov.in

hridyam.in

THANK YOU

Lifelong Care for Children with Chronic Conditions Discussion Series

Engage with the co-chairs:

- Cara Endyke Doran <u>cendykedoran@globalcommunities.org</u>
- Raoul Bermejo <u>rbermejo@unicef.org</u>

Series Dates & Case Study Discussions:

May 14th: Congenital heart disease June 11th: HIV, type 1 diabetes & sickle cell disease July 9th: Integrated NCD package of services

Time: 9 - 10:30am EDT [GMT-4]

Check out the Child Health Task Force Website for important resources!

Subgroup information, recordings and presentations from previous webinars are available on the subgroup page of the Child Health Task Force website: www.childhealthtaskforce.org/subgroups/expansion

Become a member of the subgroup: www.childhealthtaskforce.org/subscribe